

Appendix A

Genomics Internet Resources for Health Professionals

As the information highway continues to expand, Internet resources provide quick and ready access to information for both consumers and health professionals. Although hundreds of websites about genetics and genomics currently exist, the following resources support the chapters covered in this report. Please refer to the disclaimer at the end of this Appendix.

Genomics at CDC	
CDC's Office of Genomics and Disease Prevention (OGDP) http://www.cdc.gov/genomics/	This website provides information about human genomic discoveries and how they can be used to improve health and prevent disease. It also provides links to CDC-wide activities in public health genomics across the lifespan.
Public Health Genomics at CDC: Accomplishments and Priorities 2004 http://www.cdc.gov/genomics/activities/ogdp/2004.htm	This document, published in January 2005, summarizes CDC's accomplishments, priorities, and future directions in human genomics.
Educational Resources	
Genomics for Public Health Practitioners http://www.cdc.gov/genomics/training/GPHP/menu_content.html	A 45-minute introductory presentation on genomics and public health intended for public health practitioners who have minimal experience in the area of genomics as it pertains to public health.

Six Weeks to Genomics Awareness http://www.genomicawareness.org/index.htm	An online series of six presentations designed to provide public health professionals a foundation for understanding how genomics advances are relevant to public health.
Genetics Home Reference http://ghr.nlm.nih.gov/ghr/template/Home.vm	The National Library of Medicine's website about genetic conditions and the genes responsible for those conditions.
Talking Glossary of Genetic Terms http://www.genome.gov/10002096	The National Human Genome Research Institute (NHGRI) created the Talking Glossary of Genetic Terms to help people without scientific backgrounds understand the terms and concepts used in genetic research.
Your Genes, Your Health Multimedia Guide http://www.ygyh.org/index.htm	Cold Spring Harbor Laboratory explains genes, health and disease in a multimedia format.
The National Society of Genetic Counselors http://www.nsgc.org/	The leading voice, authority, and advocate for the genetic counseling profession.
National Human Genome Center at Howard University http://www.genomecenter.howard.edu/intro.htm	The National Human Genome Center at Howard University is a comprehensive resource for genomic research on African Americans.
Genetic Fact Sheets http://www.genetics.emory.edu/physicians/genetic_fact_sheets.html	Developed by the Department of Human Genetics, Emory University School of Medicine.

Educational Resources in Spanish

La Oficina de Genómica y Prevención de Enfermedades de los CDC

<http://www.cdc.gov/genomics/spanish/default.htm>

Spanish language version of the CDC's Office of Genomics and Disease Prevention website.

Genetica Websites en Espanol

http://www.ornl.gov/sci/techresources/Human_Genome/education/spanish.shtml

This website from the Department of Energy (DOE) provides information on the Human Genome Project and additional links to Genomics information in Spanish.

International Resources

The WHO Human Genetics Programme

<http://www.who.int/genomics/about/en/>

The Human Genetics Programme aims to support international activities on the development of medical genetics services in countries.

Genomics and World Health: Report of Advisory Committee on Health Research

<http://www3.who.int/whosis/genomics/pdf/genomics00.pdf>

A 2002 report by the World Health Organization.

Public Health Genetics Unit Newsletter (PHGU), U.K.

<http://www.phgu.org.uk/newsletter/newsletter.html>

The PHGU Newsletter contains news about recent research in genetics and its public health implications.

International Genomics Consortium http://www.intgen.org/index.html	A nonprofit medical research organization established to expand upon the discoveries of the Human Genome Project.
Family History	
CDC's Family History Initiative http://www.cdc.gov/genomics/activities/famhx.htm	Provides a description of CDC's Family History Initiative.
CDC's Family History Website for the Public http://www.cdc.gov/genomics/public/famhistMain.htm	Provides information for the general public about family history and how it can be used to promote health.
Morbidity and Mortality Weekly Report (MMWR) http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5344a5.htm	Link to MMWR article, "Awareness of Family Health History as a Risk Factor for Disease—United States, 2004"
U.S. Surgeon General's Family History Initiative http://www.hhs.gov/familyhistory	This initiative includes an easy-to-use, downloadable, Web-based family history tool, "My Family Health Portrait".
National Society for Genetic Counselors http://www.nsgc/consumer/familytree/	Provides information on how to collect a family history.
National Coalition for Health Professional Education in Genetics (NCHPEG) http://www.nchpeg.org/nchpeg.html ? http://www.nchpeg.org/newsletter/newsletter.asp	A newsletter for health professionals from NCHPEG's Family History Working group.

Direct-To-Consumer Marketing of Genetic Tests

Morbidity and Mortality Weekly Report (MMWR) http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5327a1.htm	Link to MMWR article, "Genetic Testing for Breast and Ovarian Cancer Susceptibility: Evaluating Direct-to-Consumer Marketing - Atlanta, Denver, Raleigh-Durham, and Seattle, 2003."
Marketing of Genetic Tests: Role of FTC http://www4.od.nih.gov/oba/SACGHS/meetings/October2003/Daynard.pdf	A PowerPoint presentation from Matthew Daynard at the SACGHS meeting in 2003.
Meeting Summary of Direct to Consumer Advertising of Genetic Tests http://www.genome.gov/12010660	Meeting convened by the National Human Genetics Research Institute in March 2004.
Direct-to-Consumer Marketing of Genetic Tests for Cancer: Buyer Beware http://www.jco.org/cgi/content/full/21/17/3191	An editorial from the Journal of Clinical Oncology.

Genomics Research

Human Genome Epidemiology Network (HuGENet™) http://www.cdc.gov/genomics/hugenet/default.htm	A global collaboration of individuals and organizations committed to the assessment of the impact of human genome variation on population health.
Human Genetics and Medical Research http://history.nih.gov/exhibits/genetics/	An online exhibit for the public providing information about the use of genetics in medicine sponsored by the National Institute of Health (NIH).

Genes and Populations http://www.nigms.nih.gov/nes/science_ed/genepop/	A series of questions and answers for patients considering participation in research studies from the National Institute of General Medical Sciences.
Human Genome Project http://www.ornl.gov/sci/techresources/Human_Genome/research/research.shtml	The Human Genome Project was completed in 2003 and this website details the research areas covered by the project.
National Institute of Environmental Health Sciences (NIEHS) National Center for Toxicogenomics (NCT) http://www.niehs.nih.gov/nct/home.htm	The NCT mission is to coordinate a nationwide research effort for the development of a toxicogenomics knowledge base.
World Health Organization's Genomics Research Center – Ask the Expert http://www.who.int/genomics/professionals/GRC_experts/en/	Send your questions about genomics to members of a judiciously selected group of health professionals in genetics and related disciplines; this group is committed to the development of genomics, public health systems and public engagement in the development of science and technology.
Harvard Medical – Partners Healthcare Center for Genetics and Genomics (HPCGG) http://www.hpcgg.org/	HPCGG's mission is to promote genetics and genomics in research and clinical medicine.

Genetic Testing

Understanding Gene Testing

<http://press2.nci.nih.gov/sciencebehind/genetesting/genetesting00.htm>

Provided by the National Cancer Institute, this website illustrates what genes are, explains how mutations occur and how they are identified within genes, and discusses the benefits and limitations of gene testing for cancer and other disorders.

ACCE

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<http://www.cdc.gov/genomics/activities/fbr.htm>

Conducted by the Foundation for Blood Research under a cooperative agreement with CDC's Office of Genomics and Disease Prevention, the ACCE Project proposed and tested a model process for collecting, evaluating, interpreting, and reporting data about DNA (and related) testing for disorders with a genetic component.

EGAPP

Evaluation of Genomic Applications in Practice and Prevention (EGAPP)

<http://www.cdc.gov/genomics/gtesting/egapp.htm>

EGAPP is a three-year model project launched in 2004 by CDC's Office of Genomics and Disease Prevention. The project's goal is to support the first phases of a coordinated process for evaluating genetic tests and other genomic applications that are in transition from research to clinical and public health practice.

Newborn Screening

Association of Public Health Laboratories (APHL) Newborn Screening and Genetics Program
http://aphl.org/Newborn_Screening_Genetics/index.cfm

The APHL Newborn Screening and Genetics program strengthens the role of public health laboratories in genetic testing and designs strategies to address changes in the newborn screening field.

March of Dimes Newborn Screening Recommendations
http://www.marchofdimes.com/professionals/682_4043.asp

Newborn screening recommendations for professionals and researchers.

National Newborn Screening and Genetics Resource Center (NNSGRC)
<http://www.genes-r-us.uthscsa.edu/index.htm>

Information and resources on newborn screening and genetics for health professionals, the public health community, consumers and government officials.

Genetic Testing for Rare Diseases

National Laboratory Network for Rare Disease Genetic Testing
<http://www.rarediseasetesting.org/>

A family of laboratories for orphan rare disease diagnostics.

GeneTests/GeneClinics
<http://www.genetests.org>

Developed for physicians, healthcare providers, researchers and others to provide information about genetic testing.

National Academy of Sciences: Human Gene Testing
<http://www.beyonddiscovery.org/content/view/article.asp?a=239>

A summary of human genetic testing that ranges from the unraveling of the nature of the gene to the social dilemmas posed by genetic testing.

Public Health Practice

CDC-Funded Centers

University of Washington

<http://depts.washington.edu/cgph/>

University of Michigan

<http://www.sph.umich.edu/genomics/>

University of North Carolina

<http://www.sph.unc.edu/nccgph/index.htm>

The CDC awarded funding to these three schools of public health, establishing the first “Centers for Genomics and Public Health.”

CDC-Funded States

**Michigan Department of
Community Health**

<http://www.MIGeneticsconnection.org>

**Minnesota Department of Health
(MDH) Chronic Disease Genomics
Project**

<http://www.health.state.mn.us/divs/hpcd/genomics/>

Oregon State Genetics Program

<http://www.oregongenetics.org>

**Utah Department of Health
(UDOH): Chronic Disease
Genomics Program**

<http://health.utah.gov/genomics>

CDC established cooperative agreements with state health departments in Michigan, Minnesota, Oregon and Utah to strengthen programs for genomics and chronic disease prevention.

Genes and Diseases

GDPInfo

<http://www2a.cdc.gov/genomics/GDPQueryTool/frmQueryBasicPage.asp>

The GDPInfo query tool allows you to define your search of the OGD P website with a combination of genes, diseases/conditions, topics and other factors.

Genetics Home Reference

<http://ghr.nlm.nih.gov/ghr/template/Home.vm>

Genetics Home Reference is the National Library of Medicine's website for consumer information about genetic conditions and the genes or chromosomes responsible for those conditions.

Gene Reviews

<http://www.geneclinics.org/servlet/access?id=8888891&key=EU5gttBEabgRZ&fcn=y&fw=wIJK&filename=/home/grcover.html>

An online publication of expert authored disease reviews from GeneTest.

Disease InfoSearch

<http://www.geneticalliance.org/DIS/index.html>

Provided by the Genetic Alliance, a tool to assist in finding specific and quality information about genetic conditions.

Websites for Genetic Disorders

<http://www.communityschoolhouse.org/websites.geneticdisorders.htm>

More than 20 genetic disorders are listed by the 21st Century Schoolhouse, with links to websites about each disorder.

Genetic and Rare Conditions Website

<http://www.kumc.edu/gec/support/>

The Medical Genetics Department of the University of Kansas Medical Center provides links to lay advocacy and support groups along with information on genetic conditions/ birth defects for professionals, educators, and individuals.

Ethical and Social Issues

NIH Bioethics Resources http://www.nih.gov/sigs/bioethics/index.html	<p>This website contains a broad collage of annotated, comprehensive URLs about bioethics.</p>
Human Genome Project, Ethical, Legal and Social Issues http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml	<p>A website sponsored by the U.S. Department of Energy.</p>
Gene-Watch-Council for Responsible Genetics (GRC) http://www.gene-watch.org/	<p>Fosters public debate about the social, ethical and environmental implications of genetic technologies.</p>
Center for Genetics and Society/ Human Genetics in the Public Interest http://www.genetics-and-society.org/index.asp	<p>A nonprofit information and public affairs organization that works to encourage responsible uses and effective societal governance of the new human genetic and reproductive technologies.</p>
HumGen http://www.humgen.umontreal.ca/int/GI.cfm	<p>An international database on the legal, social, and ethical aspects in human genetics.</p>
Ethical, Legal and Social Implications of Genetic Testing: 25 Recommendations from the European Commission (2004) http://europa.eu.int/eorg/research/conferences/2004/genetic/recommendations_en.htm	<p>The High Level Expert Group presents twenty-five recommendations on the ethical, legal and social implications of genetic testing.</p>
National Information Resource on Ethics and Human Genetics http://www.georgetown.edu/research/nrcbl/nirehg/	<p>A compilation of links, journals and other publications that offer research about ethics and human genetics from Georgetown University.</p>

Policy and Law

NHGRI Policy and Legislation Database

<http://www.genome.gov/PolicyEthics/LegDatabase/pubsearch.cfm?CFID=970614&CFTOKEN=58321499>

The National Human Genome Research Institute database contains Federal and State laws/statutes; Federal legislative materials; and Federal administrative and executive materials, including regulations, institutional policies, and executive orders.

National Conference of State Legislatures

<http://www.ncsl.org/programs/health/genetics.htm>

Includes table of genetic laws and legislation by state and topic.

Genetics and the Law Project

<http://www.genelaw.info/>

An initiative of the Council for Responsible Genetics (CRG), released an expansive, searchable online clearinghouse of information on emerging legal developments in human genetics.

Genetics Policy Database

<http://phgu.org.uk/policydb/>

A website from Public Health Genetics Unit (PHGU) listing around 1000 key policy documents in the U.K., from 1984 to the present day.

The Genetic Education Materials (GEM) Database

<http://www.gemdatabase.org/GEMDatabase/index.asp>

A searchable listing of public health genetics policy documents and clinical genetics educational materials provided by the National Newborn Screening and Genetics Resource Center.

<p>Genetics and Public Policy Center http://www.dnapolicy.org/index.jhtml</p>	<p>Information on genetic technologies and genetic policies for the public, media and policymakers. Funded through a grant from the Pew Charitable Trusts.</p>
<p>GenBiblio http://www.humgen.umontreal.ca/int/GB_q.cfm</p>	<p>GenBiblio contains a compilation of policies on human genetics and includes conventions, legislation, declarations, recommendations, guidelines and directives.</p>

Disclaimer: The CDC Office of Genomics and Disease Prevention makes this information available as a public service only. Providing these links does not constitute an endorsement of these organizations or their programs by CDC or the federal government, and none should be inferred. Exclusion of information does not mean there are no other useful resources available. The CDC is not responsible for the content of the individual organization Web pages found at these links. Note that some links may become invalid over time.